Hard-to-get-at data from difficult-to-access users

Abstract. This paper reports on the design and development of a suite of tools to collect, analyze and visualize a diverse range of data from sufferers of mental ill-health. The aim is to allow researchers and ultimately sufferers and clinicians to better understand the 'individual signatures' of factors that indicate or identify episodes of ill-health. The tools have been applied as part of a study working with clients of a mental health service that demonstrates positive results concerning the applicability and acceptability of the approach in developing a better understanding of the factors surrounding self-harm behavior.

Keywords. Apps, wearable technology, mental health, visualization

1 Introduction

The importance of context on behaviors and experiences has long been recognized in design disciplines, and many attempts by the HCI community have been made to devise or adapt methods for better understanding what people do, in the settings that they do it. Approaches to collecting data in-situ have yielded a number of tools for mobile 'experience sampling' [2], that regularly collect data from the user, for example Mappiness [8], which aims to gauge emotional responses to the current location.

In this paper we report an approach that allows us to collect 'live' data 'in the field' from users who often fall outside of the 'standard' populations, and in situations that are not typically the focus of more traditional user research methods such as evaluation studies, diary studies etc. Our approach employs an array of technologies: mobile devices, wearable computing, web applications, to allow participants to engage in a data collection process that is both autonomous and active, providing an enriched understanding of the way that physical, physiological, emotional and environmental factors can influence mal-adaptive behaviors, in this instance, that of self-harm.

This project combines both qualitative and quantitative approaches to construct an understanding of both the perception of activity, behavior and context as well a quantitative underpinning of what is actually occurring. The current paper describes the technical approach and its application to a small-scale study.

2 Background

This research project sought to create an 'ecological model of self harm', by better understanding the lives and actions of young men who have a history of self-harm. The literature on self-harm has identified a number of factors that may be implicated in the changes in mental state leading to self-harm episodes. However, such studies have tended to rely heavily on self-reports of self-harm incidents that require after-the-fact recollection.

Patient-led monitoring of symptoms is now standard practice in many areas of medicine and serves a wide variety of monitoring functions, from symptom severity to treatment side effects. However, in the area of mental health, symptom and behavioral monitoring are generally performed retrospectively and rely on self-report, creating the possibility of bias, inaccuracy and temporal effects. The case for reliably monitoring symptoms and signs, and the potential for novel mobile technology is made forcefully in a recent report of the Chief Medical Officer [3].

Several experimental attempts have been made to collect and analyze data that can afford a patient or clinician a better understanding of relevant contextual factors. Typically, however, such projects have been quite narrow in scope – either focusing only on a single condition, or employing only limited sensing, monitoring and analysis technologies. In some cases, projects have been unable to engage with actual patients – an important class of users – and have relied instead on experts and proxy test users.

The Trajectories of Depression project focused on the effects of mobility (as a proxy for activity) on depression [9]. In addition to subjective self-reports, only a single type of more objective data was captured (GPS location). Darzi and others [4] have proposed a similar approach – using data that can be readily collected by the sensors on a modern smartphone (physical activity and location) to build up a picture of peoples' lifestyle to support better weight loss strategies. Mappiness [8] demonstrates similar ideas in a more general attempt to study the effects of place and location on happiness and well-being. Again, a range of subjective and objective data is collected, and again, the capabilities of a smartphone provide a convenient platform, and also limit what data is available. The unCUT app [7] is similar in spirit to Insight, though it focuses only on self reporting, rather than the broader range of sensing and data collection used in the initial Insight prototype, and has not, as yet been tested with real patients.

In the current study, we recognized the need for a methodological approach and appropriate tools to collect a diverse range of data from real patients, allowing us to build up an understanding of both the broad context in which self-injury takes place and the individual perspective of experience and personal history on the behaviors taking place.

3 Design objectives

Difficulties in affect regulation, poor sleep and lack of physical activity are all markers of poor physical and mental health. Accurate assessment and monitoring of these and other key variables (e.g. compulsive and impulsive behaviours) have long been recognised as important, particularly for relapsing psychological problems. They can help us to understand individual symptom trajectories and potentially identify personalised relapse signatures. In order to collect this broad range of multi-dimensional, user-centred data that are not exclusively reliant on self-report, a suite of smartphone apps and other devices were brought together. The system, depicted in **Fig. 1**, includes a combination of off-the-shelf hardware and software, as well as some bespoke elements. This system supports the collection of digital diary content (text, audio and

video), location tracking, and activity and physiological data that was uploaded to a secure server, and was accessible to the research team via a web-based interface.

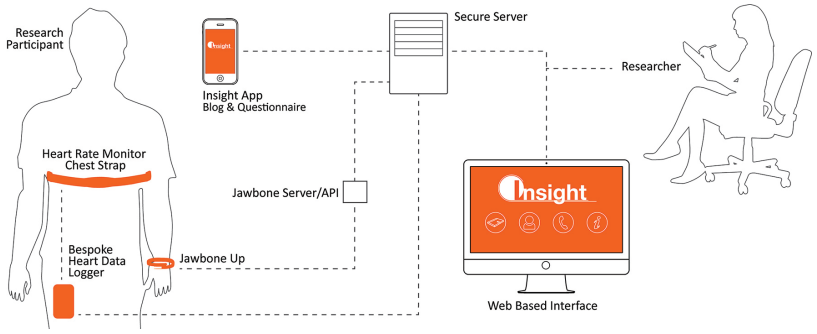

Fig. 1. Insight system structure

3.1 Digital Diary

Participants are prompted twice-daily to complete a multi-media diary ('*My Diary*') of moods and activities; intensity, duration and contextual features of any self-injurious thoughts and behavior; other risk-taking and impulsive behaviors (e.g. binge eating and drinking); flashbacks; and nightmares. Each diary entry begins with a series of closed questions consisting of check-boxes, rating scale sliders or free text entry fields (see **Fig. 2**).

Participants conclude the diary entry with a free text account of events, thoughts and feelings since the last diary entry that can incorporate audio, photographs and video. This content is uploaded to a private Wordpress 'blog' that can be used for personal recollection and reflection. Participants are also encouraged to post pictures, videos and text about their broader life histories and experiences, and record daily moods and activities ('*My Story*'). The blog-diary data, along with the uploaded questionnaire responses are also available, via the web server, to project researchers for later analysis.

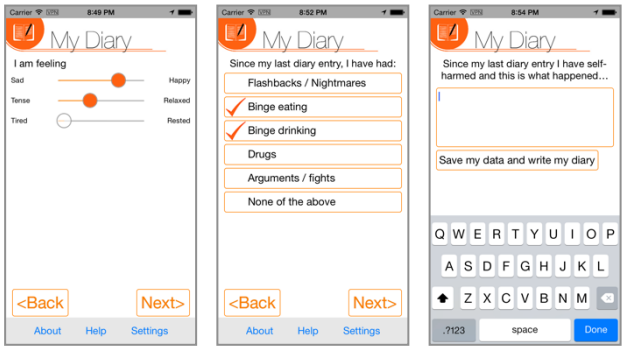

Fig. 2. The Insight App: open and closed diary question entries

3.2 Location tracking

Location and physical mobility have been implicated as factors affecting mental state [e.g. see 9], and there is evidence that specific locations may have a causal effect on self-harm behavior (e.g. because of memories triggered in a particular place).

The Insight smartphone app continuously tracks the location of the participant, and uploads location data to the secure server each time the participant uploads a diary entry. In order to manage participants' desire for privacy, location tracking can be disabled or the granularity of tracking adjusted within the app by the user.

3.3 Activity and physiological data

There are indications in the literature that identify heart rate variability (HRV) as a reliable biomarker for stress (e.g. [1], [6]). Obtaining reliable data for assessing levels of HRV over an extended period (around 3 weeks in this project), outside of the laboratory in naturalistic settings using non-invasive methods is a non-trivial task. Many commercial heart rate measurement products exist, either as 'lifestyle devices', sports training aids, or medical monitoring devices (e.g. cardiological diagnostic tools). However, none (at the time of this study) was intended to unobtrusively capture heart data over a prolonged period: many products do not monitor continuously, and those that do tend to be bulky and uncomfortable.

A bespoke heart beat data logger was developed for this project that collects data wirelessly from a commercial chest strap heart sensor. The data logger records a time-stamp each heart beat. Data is stored on a memory card for later upload, storage and integration with other data generated. The inter-beat intervals in the resultant data can be used to calculate heart rate and HRV. This sensing method enables reliable data to be collected in a relatively non-invasive and power efficient way.

While collecting continuous heart beat data proved required bespoke hardware, the measurement of other indicators of behavior was made simpler by the range of readily available activity tracking devices. The project made use of Jawbone UP[1] wristbands, to sense physical activity, and sleep quality and duration (see **Fig. 3**).

[1] http://jawbone.com

Fig. 3. Data collection using Jawbone UP, chest-strap heart monitor, custom data-logger and smartphone app

4 Making sense

A key aim has been to provide a means of analyzing data so researchers can gain insights into factors and variables influencing a person's mental state. Of particular interest is the identification of individual signatures, indicative of an person's mental state, and which may be connected with a deterioration or recurrence of self-harming behavior. The aim is therefore not (only) to make data amenable to statistical analysis across a cohort of participants. Rather the aim is to support a process of investigation in which patterns, possibly highly individual in nature, may be discerned.

To this end, the Insight system provides two main visualization tools. The Geo-view (**Fig. 4**) shows the locations logged by the smartphone app, overlaid on a map.

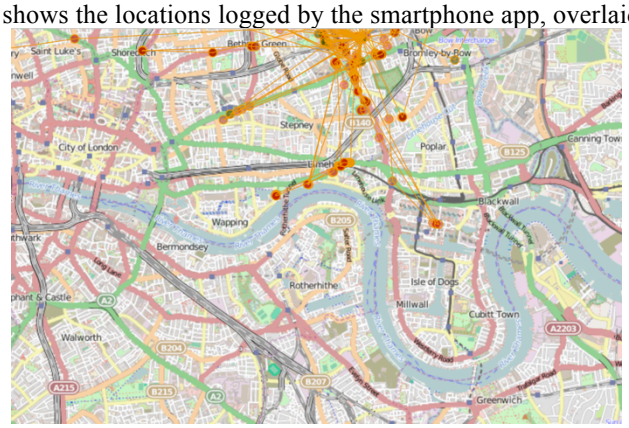

Fig. 4. Geo-view showing user's movement

The second visualization is a timeline that plots a broad range of data over time (**Fig. 5**). This timeline chart shows measured variables (e.g. activity, sleep quality, heart rate and variability) and subjective reports (e.g. responses to questions about affective state) as well as discrete events (e.g. reports of self harm).

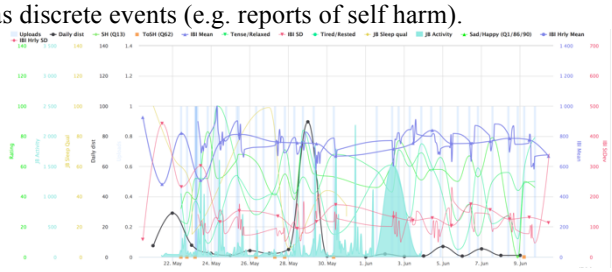

Fig. 5. Data view showing sensor data and diary question responses

One thing that is clear from **Fig. 5** is that the data in this fairly raw form presents a confusing and complex picture, and is likely to be of limited use in discerning any

pattern. However, the view provides filtering and zooming, allowing the user to interact with the data to investigate more specific patterns and relationships (e.g., see **Fig. 6**). Currently, data visualizations are at a prototype stage, and suitable for researchers rather than patients. Future development will create visualizations that enable patients to explore and better understand their own behavioral signatures.

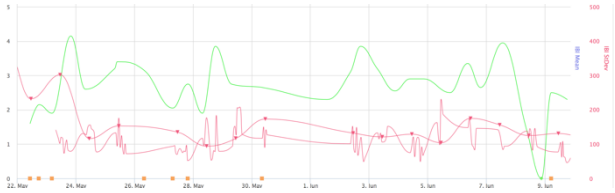

Fig. 6. Zoomed and filtered data view to investigate possible relationships between HRV, affective state and reported thoughts of self-harm

5 An ecological study of self-harm

The technology setup was trialed with 5 users who had a history of self-injury, and who were recruited through a mental health service of which they were clients. Each participant was asked to take part in the study for a period of around 3 weeks, though two participants chose to take part for considerably longer. **Table 1** summarizes participation in the study, indicating the volume and variety of data collected.

Table 1. Summary study data

Participant no.	Days in study	No. of days made 'My Diary' entries	% of days made 'My Diary' entries	Total no. of 'My Diary' entries	Total no. of 'My Story' entries	Thoughts of Self Harm	Self Harm
1	79	65	82.28	99	128 (+ 4 videos/photos)	36	15
2	21	21	100	43	60 (+ 30 videos/photos)	13	0
3	21	13	61.90	15	4 (all text)	6	0
4	21	18	85.71	36	12 (+ 1 photo)	8	1
5	49	35	71.43	37	5 (all text)	29	5

A thorough analysis of the data, and presentation of a 'model of self harm' is beyond the scope of the current paper. However, it is worth noting that all participants continued in the study for the expected duration, persisting in making diary entries throughout (making an average of around 1.3 entries per day). No significant drop-off was observed, with participants continuing to contribute throughout the study (though Jawbone UP and heart rate data was patchier later in the study as batteries ran out).

Post-study, participants were de-briefed in an interview with a member of the project team that explored, among other things, the experience of participation and use of the tools. Reactions to the technology, its usability, and reflections on the value of participation, were generally positive. For example, one participant (P5) reported that the study had helped him "*express some of what I'm going through that's in my head down as data. So it has, yeah, I've found it beneficial. [especially] after I've self-harmed because… I sort of put the self-harm into the diary log or something and I can put my feelings and I really feel down and like I come up a bit so that's probably been the best, you know*". Another participant reported using the digital diary app to vent his frustrations in a safe way, "*I'm alone but I got my diary to keep me company. I can rant on here and not get told off or nicked…I like to fact I got a mini haven in my hand I talk like it's a mate but it don't hit me or kick me in the face"* (P1); whilst P2 told us that he planned to invest in his own Jawbone wristband at the end of the research, as this had helped him with "*...keeping me in touch with my sleep patterns and when to go to bed, which is fantastic*". The same participant also reported watching his own video-diaries back and then showing them to his therapist "*so they can see what I am actually like when I'm feeling depressed and down … I don't show that side to me. I am just happy go lucky person but actually in real life I am not. So again doing the research is helping me again.*"

6 Conclusions

This research-in-progress has designed developed a novel suite of software and hardware tools to support the collection, analysis and visualization of a range of self reports and sensed data from people with a history of self-harming behavior. The approach has been trialed on a small but substantial study in which data was collected over a period of more than 3 weeks from 5 users. Initial analysis of the data, as well as post-study interviews suggest a very positive response to the approach, with the experience of the technology being generally positive, and the ability to record and reflect being regarded as highly beneficial.

Work is progressing in several areas. The analysis process, and the interactive visual analytic tools needed to make sense of a mass of complex, heterogeneous data is progressing towards the original aim of informing a model of self-harm, that explores links between contextual variables and behavior.

The aim of this project was certainly not to develop a therapeutic tool (although the study indicated a positive effect in taking part and in the reflective process and gathering of personal commentary). Indeed, the intended users of the data and visualizations of it are mental health researchers, rather than patients or clinicians (and, apart from the blog elements, users don't have access to the recorded data other than through the project team). However, giving patients easy access to their data, and exploring the use of such data in personal and clinical settings is a natural direction for the project to take.

A further set of developments under active investigation concern making the technology more configurable (e.g. to easily create bespoke content for a particular study),

personal (e.g. identifying data relevant to an 'individual signature' of a particular patient), and general (e.g. allowing a range of sensors and visualization tools to be incorporated). On this latter point we are exploring the use of extensions of quite general 'm-health' frameworks such as *Open mHealth* [5].

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7 References

1. Brosschot, J.F. et al.: Daily worry is related to low heart rate variability during waking and the subsequent nocturnal sleep period. Int. J. Psychophysiol. 63, 1, 39–47 (2007).
2. Cherubini, M., Oliver, N.: A Refined Experience Sampling Method to Capture Mobile User Experience. Workshop on Mobile User Experience Research - CHI'2009. (2009).
3. Chief Medical Officer: Annual Report of the Chief Medical Officer 2013, Public Mental Health Priorities: Investing in the Evidence, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/351629/Annual_report_2013_1.pdf, (2013).
4. Darzi, A.: Quantified-self for obesity: Physical activity behaviour sensing to improve health outcomes from surgery for severe obesity. EPSRC project EP/L023814/1, http://gow.epsrc.ac.uk/NGBOViewGrant.aspx?GrantRef=EP/L023814/1.
5. Estrin, D., Sim, I.: Open mHealth Architecture: An Engine for Health Care Innovation. Science. 330, 6005, 759–760 (2010).
6. Horsten, M. et al.: Psychosocial Factors and Heart Rate Variability in Healthy Women. Psychosom. Med. 61, 1, (1999).
7. Lederer, N. et al.: unCUT: Bridging the Gap from Paper Diary Cards Towards Mobile Electronic Monitoring Solutions in Borderline and Self-Injury. 3rd Int. Conf. on Serious Games and Applications for Health. IEEE (2014).
8. MacKerron, G., Mourato, S.: Happiness is greater in natural environments. Glob. Environ. Change. 23, 5, 992 – 1000 (2013).
9. Musolesi, M.: Trajectories of Depression: Investigating the Correlation between Human Mobility Patterns and Mental Health Problems by means of Smartphones. EPSRC project EP/L006340/1, http://www.cs.bham.ac.uk/research/projects/tod.